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# Representing the patient perspective in the treatment of atrial fibrillation

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**This editorial refers to ‘Validation of the AF-QoL, a disease-specific quality of life questionnaire for patients with atrial fibrillation’ by F. Arribas *et al.*, on page 364.**

Atrial fibrillation (AF) is the most common heart rhythm disorder,<sup>1</sup> associated with increased risk of morbidity, mortality, hospitalization, poor quality of life (QoL), and increased health care utilization.<sup>2</sup> Atrial fibrillation is considered to be a growing epidemic, with the rise in the prevalence of AF primarily attributed to the aging population and improved treatment options for coronary artery disease, heart failure, and hypertension, leading, in turn, to improved survival in these subsets of patients.

In the treatment of cardiovascular disease, there is an increasing recognition that it is important to assess the impact of disease on patients’ daily functioning and QoL, thereby representing the patient’s perspective.<sup>3</sup> Patient-reported health status and QoL have been shown to predict mortality, independently of traditional biomedical risk factors both in coronary artery-disease and heart failure.<sup>4</sup> No such data are as yet available in patients with AF. However, given that there seems to be little overlap between indicators of AF disease severity and QoL,<sup>5,6</sup> poor QoL may also likely be independently associated with prognosis in patients with AF. Moreover, subgroups of patients with heart disease indicate that they prefer symptom improvement and well-being over prolonged survival.<sup>7</sup> As such, treatments for AF should also be evaluated with respect to their influence on QoL and general well-being. Unfortunately, QoL is not commonly assessed in clinical cardiology practice today, nor it is possible to derive a proxy measure for QoL based on factors assessed routinely. Hence, patient-rated QoL deserves to be studied in its own right, also because it may provide information about the most appropriate treatment, and be used as a performance measure by which to evaluate the effects of treatment and judge the quality of care given to patients.<sup>3</sup>

A range of generic measures for assessment of QoL are available, including the Short Form Health Survey (SF) 12 or 36, that

are frequently used in patients with somatic disease. However, generic measures do not tap symptoms pertinent to patients, and may therefore be less sensitive to capture changes in QoL over time when compared with disease-specific measures. In contrast, few validated and standardized disease-specific instruments exist that tap AF-specific symptoms, with current measures having some shortcomings.<sup>8</sup>

Arribas *et al.*<sup>9</sup> present the results on the AF-QoL-18, an 18-item disease-specific measure developed to assess QoL in patients with AF. The development of AF-QoL-18, from item generation to item selection and reduction in the number of items, has previously been described.<sup>10</sup> In this paper, the authors provide important additional information on the instrument, subjecting it to a rigorous examination with respect to its psychometric properties. Their results confirm and further elaborate the instrument’s discriminating validity with respect to its ability to distinguish between patients who present with AF-related symptoms vs. no symptoms, and its reliability in terms of a good internal consistency (Cronbach’s alpha of 0.92 for the total scale and levels higher than 0.80 for the subdomains) and test–retest reliability.<sup>9</sup> Importantly, the authors also examined and established that the instrument is sensitive enough to capture changes in AF symptoms over time. The latter finding is important, as it indicates that the AF-QoL-18 is suitable to use as an outcome measure in clinical trials and observational studies, but also that it is appropriate to use as a performance measure in clinical practice to evaluate the influence of treatment and medical care.

With its 18 items, the AF-QoL-18 comprises little burden to patients and to clinical practice when compared with generic measures such as the SF-36. An additional advantage of the AF-QoL-18 is that it is a multi-dimensional measure, capturing three QoL domains of psychological, physical, and sexual activity. The psychological domain taps depression and cardiac anxiety; the physical domain fatigue and vitality; and the sexual domain sexual activity and fear of being sexually active. Although the cross-cultural validity of the measure still needs to be established, the preliminary data on the AF-QoL-18 look promising in terms of

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filling the gap in the armamentarium of instruments that we have available for the assessment of QoL in AF patients.

In conclusion, time has come to consider including a QoL measure, such as the AF-QoL-18, as part of standard assessments in clinical practice, in order to evaluate the impact of AF on patients. This information is likely to provide additional value to the current standard assessments, and may help evaluate the standard of care given to patients in order to determine whether their treatment needs to be optimized.<sup>3</sup> The AF-QoL-18 may also be used as a primary outcome in trials because of its sensitivity to tap change, if a reduction in AF symptoms and improvement of QoL are the intended outcome. Moreover, the measure could be used in combination with other outcomes, because the use of multiple outcomes is likely to better capture the complexity of AF and disease burden to patients.<sup>11</sup> One potential caveat to bear in mind when using a QoL measure in AF is that AF recurrences in symptomatic patients may not all be attributable to AF but to other disease-causing processes.<sup>11</sup>

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